

CHILDREN'S REHABILITATIVE SERVICES 2006 FAMILY CENTERED SURVEY

INTRODUCTION

The mission of the ADHS Children's Rehabilitative Services (CRS) program is to improve the quality of life for children by providing family-centered medical treatment, rehabilitation, and related support services to enrolled individuals who have certain medical, handicapping, or potentially handicapping situations. CRS clinics provide interdisciplinary, multi-specialty care at four regional clinics throughout Arizona.

The CRS Program provides preventive and urgent care related only to specific qualifying conditions. Basic preventive care such as immunizations, and treatment for acute conditions such as infectious diseases are not covered by CRS. However, CRS specialists manage the overall care for what are often complicated medical conditions, leading to more appropriate utilization of services, and minimizing the need for emergency care.

A central philosophy of the CRS program is that the family is the center and the most important participant in the system of care for children with special healthcare needs (CSHCN). Based on this philosophy, the Family Centered Survey was created in 1997 and was conducted every two years to inform ADHS about the perception of the services received through the CRS program.

Beginning with the AHCCCS contract year ending June 30, 2006, a new survey process was designed. This new survey will be conducted annually and is substantially different than the previous version. Consequently, findings from the 2006 survey will not be compared to previous survey results. The new survey tool is based primarily on the Consumer Assessment of Healthcare Providers and Systems (CAHPS) 3.0 Medicaid Managed Care Child Questionnaire, with modifications to accommodate the special population and program characteristics of CRS.

The 2006 Family Centered Survey was a telephone survey administered to a representative sample of active AHCCCS-enrolled CRS members under the age of 21. The overall response rate for the survey was 55%. Please see Appendix A for a description of the study methodology, Appendix B for a copy of the study tool, Appendix

C for a complete breakdown of responses statewide, and Appendix D for a comparison of responses by site. Throughout the document, the number of each question is listed in parenthesis as results are presented to provide for a quick reference to materials in appendices.

FINDINGS

The mean age of children represented by respondents was 9.1 years, with nearly 60% of children between the ages of 4 and 14; 55% were male, and 48% were of Hispanic or Latino descent. Most of the members (61.7%) spoke English as their main language at home, with an additional 23.0% speaking mainly Spanish at home. The most common diagnostic condition was related to nervous system (33.4%), followed by circulatory system (20.3%), musculoskeletal/connective tissue disorders (15.4%), sense organs (10.4%), endocrine/metabolic (4.3%) and digestive system (0.8%).

Overall Health and Health Care

Respondents were asked to rate their child's overall health on a five-point scale ranging from excellent to poor (Q30). Nearly 60% of respondents characterized their children's health as excellent or very good, with an additional 27% reporting a health rating of good. Thirteen percent of respondents characterized their child's health as fair or poor. When asked to rate the overall CRS health care (Q27), with 0 being the worst health care possible and 10 being the best care possible, the average rating was 8.9 (CI=8.7, 9.1). Differences in ratings between contractor sites were not statistically significant.

Specialty Physician Availability and Rating of Care

Eighty-five percent of members had seen a CRS specialist in the past 12 months (Q1). Of those members who did not see a CRS specialist, less than one quarter (23%) had attempted to get an appointment (Q2). Most parent/guardians (76.8%) reported that it was not a problem to see a CRS specialist that their child needed to see, 15.0% said it was a small problem, and 8.2% said it was a big problem (Q3). The average rating on a scale from 0 to 10, with 10 being the best specialist possible, was 8.9, and 86.2% (CI= 7.3, 10.6) of respondents gave their child's specialist a score of 8 or higher (Q4). Another 12.2% rated their specialist from 4-7, and 1.5% rated their specialist between 0 and 3.

Access to Care

Just over one-third of respondents called the CRS clinic during regular clinic hours to get help or advice for their child (Q5), the majority of whom (79.2%) reported usually or always getting the help or advice they needed (Q6). Respondents were also asked about the number of emergency room visits made by their child. Less than 20% reported that their children visited an emergency room for their CRS condition (Q9).

AHCCCS has appointment standards for both primary care and specialty care. All of the care delivered at CRS clinics is specialty care and only those AHCCCS standards that relate specifically to specialty care apply to CRS. The following standards are outlined in the AHCCCS contract with CRS:

- For a CRS recipient with a medically urgent need, the CRS recipient must be seen according to the needs of the member and no later than 72 hours of the request.
- All other clinic appointments must be scheduled within 45 calendar days or less of referral, depending on the need of the CRS recipient's medical condition.
- A recipient's waiting time for an appointment must not exceed 45 minutes, unless the provider is unavailable due to an emergency.

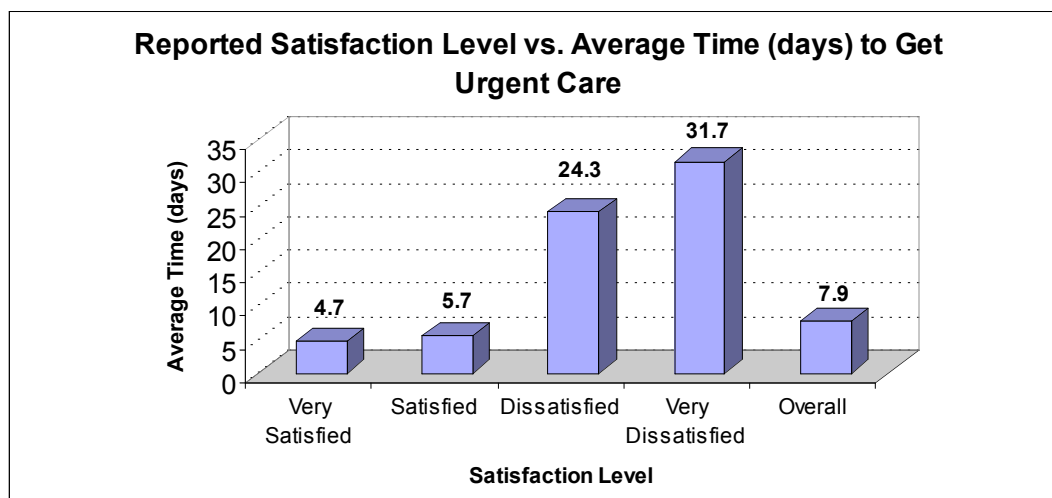
65.1% Received Medically Urgent Care within 72 Hours of Request

When members call a CRS clinic, a triage system is used to determine whether the needed service is covered by CRS or the child's primary health care plan. Urgent requests may involve conditions that are not covered under CRS, in which case, it is the responsibility of CRS to refer the patient back to their primary care physician and coordinate the care. When the condition is covered by CRS, a determination is made as to what kind of need the patient has, and whether it is more appropriate to go to a physician's office or be seen at a clinic at the next scheduled visit. (Physicians hold certain specialty clinics only on certain days.)

Survey respondents were asked whether in the past year their children "needed care right away for their CRS condition" and if so, how long they had to wait to get care at a CRS clinic (Q7). These questions were used to assess compliance with the urgent care standard. The majority of respondents (64%) reported that their child did not need urgent care for their CRS condition. Of those who did, 65.1% (CI=57.3, 72.9) said they

were able to get it in a CRS clinic within 72 hours (Q8). Differences in compliance rates between contractor sites were not statistically significant.

Over 80% reported being satisfied or very satisfied with how long it took to get care (Q10). There were no significant differences in satisfaction level by site. The average length of time reported to get urgent care was 7.9 days (CI=5.2, 10.6), with responses ranging from within 24 hours to within two months. Those who reported being very satisfied had an average wait of 4.7 days, whereas those reporting being very dissatisfied had an average wait of 31.7 days.

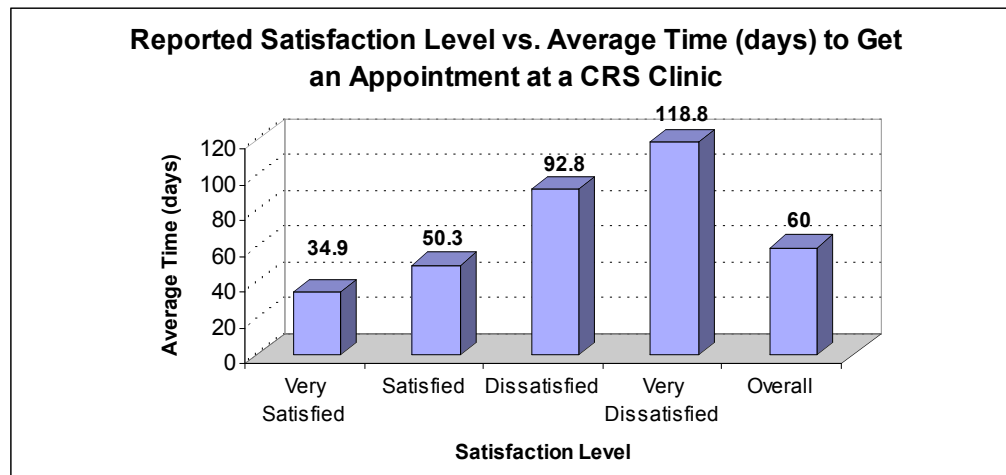


61% Received Appointment within 45 Days

Two-thirds of respondents reported calling a CRS clinic for an appointment in the past 12 months (Q11). Of those, 61.0% (55.2, 66.8) were able to get one within 45 days. Excluding Yuma, there were statistically significant differences in compliance rates between contractor sites, with Tucson having the highest compliance rates (72.5%), followed by Phoenix (51.6%), and then Flagstaff (31.8%). An insufficient number of Yuma's site members responded to the question to be able to include them in this statistical test. The majority (80%) reported being satisfied or very satisfied with how long it took to get their appointment. There were no statistically significant differences by site.

The average length of time that participants reported waiting to get an appointment at a CRS clinic was 60 days, with responses ranging from 1 day to two

years. Very satisfied members waited an average of 35 days, as compared to very dissatisfied members waiting an average of 118 days (Q10).



86% Waited Less Than 45 Minutes before Being Taken to Exam Room

When respondents were asked to report their wait time before being taken to the exam room, 86.2% (CI=82.4, 90.2) reported that they usually waited 45 minutes or less (Q13). Differences in compliance rates between contractor sites were not statistically significant.

Member Service/Treatment

Several survey items also asked about the way that children and their families were treated by clinic staff. Nearly 85% of respondents were always treated with courtesy and respect (Q14), approximately 75% of respondents felt that the clinic staff were always as helpful as they should be (Q15). Similarly high proportions are reported for the remaining customer service measures. More than three-fourths said that CRS doctors or other health providers always show respect for what they had to say (Q19), 80.1% said that CRS doctors and other providers always make it easy to discuss their questions and concerns (Q20), and 77.9% said that they always had their questions answered by their CRS providers (Q21).

These findings are consistent with anecdotal comments that CRSA staff hear from families of children with special health care needs. At CRS clinics, youth say that they do not feel so conspicuously different. Clinic staff know them and understand their

conditions. CRS Clinics are one place where children and youth do not have to explain how they are different and their need for special accommodations like accessible restrooms and waiting areas with sufficient space for their equipment.

It is widely accepted that it is a best practice for families with children with special health care needs to have families involved in all levels of decision making, and the CRS Program ascribes to this philosophy. Several questions were asked regarding the processes by which decisions about the child's healthcare were made. Just over half of respondents (53.1%, CI= 47.5, 58.7) reported decisions about their child's healthcare being made during CRS visits (Q23). Of these respondents, 76.4% reported usually or always being offered choices about their child's healthcare (Q24), and nearly 75% reported usually or always being asked to tell the healthcare provider what choices they prefer (Q25). Nearly 90% of respondents reported that they were usually or always involved as much as they wanted when decisions were made (Q26).

Several survey items also addressed communications between families and CRS clinic staff, including the need for translation services, which are an important component of a culturally competent program. Families were asked about the need for and the delivery of translation services, as well as the clinic staff members' ability to both listen carefully to families and explain things to them in a way that family members could understand. Over three-fourths of respondents (77.4%) reported that clinic staff always listens carefully to them (Q16), and a similar proportion (78.7%) reported that clinic staff always explained things to them in a way they could understand (Q18). Just over one-fourth of respondents (26.4%) reported needing an interpreter (Q28), and 86.4% of these individuals reported always receiving translation and interpretation services (Q29).

DISCUSSION

It is remarkable that in a population of children with severe medical conditions, that nearly 87% of respondents characterize their children's health as either excellent, very good, or good. Overall, most respondents rated the care they received through CRS highly, and families receiving services are for the most part happy with the care they are receiving, and feel that they are well informed and involved in the decisions regarding their children's care. In general, respondents felt that clinic staff listen carefully to them,

treated them with courtesy and respect, and explained things in a way they could understand. Interpreters were usually available for those who needed translation services. Overall, survey respondents rated their CRS care at 8.9 on a 0-10 scale, with 10 being the highest level of care possible.

Less than 20% of respondents reported their children going to the emergency room for their CRS conditions in the past year. This percent is higher than what was found in a recent analysis of claims data, and it is possible that parents and providers may not similarly attribute emergency room visits to a CRS condition. For example, the parent of a child with spina bifida who has a head shunt may go to the emergency room thinking that the child has a shunt failure or an infection related to the shunt. If this cause is ruled out in the emergency room, it may be that the parent remembers that visit as caused by the spina bifida, even though it may be an infection from some other source. Even otitis media with a temperature may result in an emergency room visit as parents are alert to possible threats or complications because of their CRS condition. It is often difficult for parents and providers alike to navigate the complicated rules for eligible conditions and services.

Information was collected to evaluate compliance with AHCCCS standards for access to care for specialty services. While 86% of respondents reported waiting times in the office within standards (45 minutes), compliance was much lower for urgent care and regular specialty care. Approximately 65% reported being able to access urgent care within the AHCCCS standard of 72 hours, and 61% reported being able to obtain an appointment for a specialist within the AHCCCS standard of 45 days. Eighty percent were satisfied with how long it took to get care.

Although it was not an original focus of the survey, a high proportion of wrong or disconnected phone numbers were discovered. This poses a problem not only for contacting members by telephone for survey purposes, but more importantly, to contact patients for purposes related to their care. As a result of this study, several recommendations will be considered:

1. Train the provider community on what is and is not a CRS-eligible condition and service.

2. Expand telemedicine capabilities and resources to improve compliance scores for access to care.
3. Share results of all analysis with CRS contractors and explore opportunities for improvement to access to care.
4. Work with sites to increase number of correct telephone numbers in their records.
5. Post results of survey to OCSHCN website.
6. Repeat survey annually to continually monitor compliance and satisfaction levels.

APPENDIX A: METHODOLOGY

The 2006 Family Centered Survey was a telephone survey administered to a representative sample of active AHCCCS-enrolled CRS members.

Sample Selection

The sampling frame included all CRS members of 21 years of age or less who were continuously enrolled in CRS and an AHCCCS Health Plan between May 1, 2005 and April 30, 2006. Members with a gap in enrollment of more than 30 days were excluded. The sampling frame included a total of 13,786 members. A sample size of 384 was calculated to tolerate no more than a 5% margin of error at a 95% confidence level, using the following formula:

$$n = \frac{z^2 p(1-p)}{E^2} = \frac{1.96^2 * 0.5 * 0.5}{0.05^2} = 384$$

where n = minimum sample size,

z = the distance from the mean associated with confidence level (1.96 for a 95% confidence level),

E = margin of error, (.05) and

p = the estimated proportion expected to be associated with a given value of a variable (the most conservative assumption =0.5).

Assuming a 50% response rate, the sample size was doubled, resulting in 768 members. A random sample was then drawn using SPSS version 13.0.

It is important to note that even though this was a telephone survey, all members were included in the sampling frame, even if they did not have a telephone number in the CRS database. Only five members were sampled who did not have a telephone number on file in the CRS system. The clinic sites were contacted and asked for telephone numbers for these members. Researchers were able to obtain a telephone number for all but one member.

Survey Administration

The survey tool is based primarily on the Consumer Assessment of Healthcare Providers and Systems (CAHPS) 3.0 Medicaid Managed Care Child Questionnaire, with modifications to accommodate the special population and program characteristics of CRS (see Appendix B). The tool was translated into Spanish to accommodate the high percentage

of Spanish-speaking families in the CRS program. A translation service was available to translate into other languages; however, only one request for translation (into Farsi) was identified. Oral translation services are only available during regular business hours. It was decided that the difficulties involved with scheduling the service around multiple contacts in such a tight timeframe would be too challenging.

The survey was administered by contracted graduate students from the Sociology Department of Arizona State University. In addition, two OCSHCN staff members fluent in Spanish conducted interviews with Spanish-speaking members. The data entry tool was pre-populated with members' contact information and key demographic variables. Interviewers were trained on the data entry tool and the automated tool's ability to capture data accurately was verified before survey implementation. In addition, training about the fundamental aspects of how CRS clinics operate was conducted. Sometimes, members contacted through the survey sought other information or resources and staff took the opportunity to refer them to appropriate services. On occasion, something that the member told a surveyor resulted in an official grievance being filed.

Members were tracked using cards containing their contact information, as well as the date, time and result of each survey attempt. Cards were then organized according to the number of attempts made, need for translation, and the preferred time of day to call the member, when indicated. Calls were made between the hours of 9am to 8pm weekdays, and 10am to 5pm on weekends.

After a first contact was attempted for the entire sample, wrong numbers were identified and listed by clinic sites, who were asked to research the list and send back accurate phone numbers. A total of 12 attempts were made for each member, and when all attempts had been made, survey administrators checked cards to ensure that attempts had been made in four distinct time ranges: mornings, afternoon, evenings, and weekends. Survey administration began May 22nd, and continued until June 16th, 2006.

Analysis

Data management and analysis were performed using SPSS version 13.0. Data was imported from the data entry tables into SPSS. Response rates and key outcomes were calculated by site. Within the body of this report, only valid responses are displayed (i.e., valid responses exclude those responses which were either not applicable or missing).

Appendix C is a complete breakdown of statewide results including missing values, and Appendix D is a comparison of results by site.

Ninety-five percent confidence intervals were calculated for point estimates using SPSS. Confidence intervals for proportional estimates were calculated using the following formula:

$$\hat{p} \pm z \sqrt{\frac{p(1-p)}{n}}$$

Where \hat{p} = the calculated proportion of a given variable

z = the distance from the mean associated with confidence level (1.96 for a 95% confidence level)

n = the number of respondents

When findings were presented as statistically significant, differences in proportions or means tested at $p < .05$.

Results

Of the 768 CRS members selected, 395 were successfully contacted and completed the survey. Forty-nine selected members stated that they were no longer receiving services through CRS, decreasing the total eligible sample to 719. The 395 completed surveys, therefore, represent an adjusted response rate of 54.9%. Response rates at the site level varied from a low of 40.5% to a high of 58.7%. Nearly one-third (29.7%) of selected members could not be reached due to wrong or disconnected numbers.

Table A1: Family Centered Survey Response Rates, by Site, n=719*

CRS Regional Clinic Site	Sampled Members	# of Survey Respondents	Response Rate
Phoenix	443	260	58.7%
Tucson	163	84	51.5%
Flagstaff	79	32	40.5%
Yuma	31	19	61.3%

*3 members had missing site information.

Demographic Characteristics of Respondents and Nonrespondents

The mean age of children represented by respondents was 9.1 years, with nearly 60% of children between the ages of 4 and 14; 55% were male, and 48% were of Hispanic or Latino descent. Most of the members (61.7%) spoke English as their main language at home,

with an additional 23.0% speaking mainly Spanish at home. The most common diagnostic conditions related to nervous system, circulatory system, and musculoskeletal/connective tissue disorders.

Unless all of a selected sample responds to a survey, there is always the possibility that those who did not respond would have answered questions differently than those who did, which is referred to as nonresponse bias. Overall response rate is one way to evaluate the potential for nonresponse bias, with higher response rates lessening the potential for nonresponse bias. Another way to evaluate the potential for nonresponse bias is to compare respondents and nonrespondents on known characteristics. Variables such as age, race, ethnicity, and enrolling diagnosis were compared for respondents and nonrespondents. The two groups were generally similar in terms of age, ethnicity, and enrolling diagnosis, with no statistically significant differences between respondents and nonrespondents. Race data that was pulled from the CRS system was inadequate to allow for a comparison, as over 80% of respondents had no known race category. Demographic characteristics of respondents and nonrespondents are displayed in Table A2.

Table A2: Demographic Characteristics of Respondents vs. Non Respondents, 2006 CRS Family Centered Survey, n=719

Characteristic	Respondents		Non-Respondents	
	n	%	n	%
Age - Mean (95% CI)	9.1(3.6,14.7)		9.8 (4.2,15.4)	
1-3	83	21.0	55	17.0
4-9	128	32.4	102	31.5
10-14	100	25.3	86	26.5
15-17	52	13.2	43	13.3
18-21	32	8.1	38	11.7
Male Gender	218	55.2	163	50.3
Ethnicity – Hispanic or Latino descent	190	48.1	132	40.7
Enrollment Diagnosis by Type				
Nervous System	132	33.4	83	25.6
Circulatory System	80	20.3	60	18.5
Musculoskeletal/Connective Tissue	61	15.4	59	18.2
Sense Organs	41	10.4	53	16.4
Digestive System	31	0.8	19	5.9
Endocrine/Metabolic	17	4.3	16	4.9

Appendix B

Family Centered Survey

All information that would let someone identify you or your family will be kept private. The Arizona Department of Health Services, Office for Children with Special Health Care Needs will not share your personal information with anyone without your OK. You may choose to answer this survey or not. If you choose not to, this will not affect the benefits your child receives.

If you want to know more about this survey, please call Heather Dunn at (602) 364-2286.

Name of the child: _____ Gender of child _____

Qualifying Condition: _____

Parent/guardian Name: _____

Phone number: _____

- ☐ Phone disconnected
- ☐ No answer, **RECORD DATE, TIME AND OUTCOME**
- ☐ Phone answered

Hello, this is (INTERVIEWER NAME) _____ calling from Arizona Department of Health Services. We'd like to talk with you about your experiences with the Children's Rehabilitative Services Program. Your answers will help us to make the program better. May I please speak to (Parent/Guardian name) _____?

- ☐ If person is parent/guardian, **GO TO CONSENT**
- ☐ No one by that name at this phone number, **RECORD DATE, TIME AND OUTCOME**
- ☐ Not available

We need to talk with the parent or guardian who lives in this household who knows the most about the health care that (child's name) _____ receives through CRS.

Would that be you?

- ☐ Yes, **GO TO SURVEY INTRODUCTION**
- ☐ No

Who would that be? _____. Is he/she available?

- ☐ Yes **GO TO SURVEY INTRODUCTION**
- ☐ No, **GO TO CALL BACK**
- ☐ Child is over the age of 18 and makes their own health care decisions, **THANK THEM FOR THEIR TIME AND SAY GOOD-BYE.**

CALL BACK:

- | | |
|---|---|
| <input type="checkbox"/> AM _____ | <input type="checkbox"/> Need Spanish speaker |
| <input type="checkbox"/> PM _____ | <input type="checkbox"/> Other language _____ |
| <input type="checkbox"/> Weekends _____ | |

SURVEY INTRODUCTION

We are conducting a satisfaction survey of families who receive health care services through Children's Rehabilitative Services (CRS). Your family has been selected at random to be included in the study. Your answers will help us to make the program better.

You may choose to do this interview or not. If you do, your responses will be kept private. Your decision to do the interview will not affect any benefits you get. The questions should take about 15 minutes to answer.

Do you wish to participate in this survey?

- ☐ Parent/guardian agrees
- ☐ Parent/guardian refuses, Thank them for their time and say good-bye.

IF THE FAMILY MEMBER DOES NOT HAVE TIME TO PARTICIPATE IN THE INTERVIEW NOW, GO TO CALL BACK.

I'd like to begin the interview now, but before we begin, do you have any questions about the survey?

If the parent or guardian has additional questions or concerns have them call Heather Dunn at (602) 364-2286.

Our records show that your child (_____) is now in CRS. Is that right?

- ¹☐ Yes
- ⁰☐ No, Thank them for their time

1. In the last 12 months, did your child see a CRS specialty doctor?

¹☐ Yes → If Yes, Go to Question 3

⁰☐ No → If No, Skip Question 4

2. In the past 12 months, did you try to get an appointment with a CRS specialty doctor?

¹☐ Yes

⁰☐ No → If No, Go to Question 5

3. In the last 12 months, how much of a problem, if any, was it to see a CRS specialty doctor that your child needed to see?

¹☐ A big problem

²☐ A small problem

³☐ Not a problem

4. We want to know your rating of the CRS specialty doctor your child saw most often in the last 12 months. Using any number from 0 to 10, where 0 is the worst specialist possible, and 10 is the best specialist possible, what number would you use to rate your child's specialty doctor?

⁰☐ 0 Worst specialist possible

¹☐ 1

²☐ 2

³☐ 3

⁴☐ 4

⁵☐ 5

⁶☐ 6

⁷☐ 7

⁸☐ 8

⁹☐ 9

¹⁰☐ 10 Best specialist possible

5. In the last 12 months, did you call the CRS clinic during regular clinic hours to get help or advice for your child?

¹☐ Yes

²☐ No → If No, Go to Question 7

6. In the last 12 months, when you called during regular CRS clinic hours, how often did you get the help or advice you needed for your child?

¹☐ Never

²☐ Sometimes

³☐ Usually

⁴☐ Always

7. In the last 12 months, when your child needed care right away for their CRS condition, how satisfied were you with how long it took to get care as soon as you wanted at a CRS clinic?

¹☐ Very satisfied

²☐ Satisfied

³☐ Dissatisfied

⁴☐ Very dissatisfied

⁵☐ My child did not need urgent care
→ Go to Question 9

8. In the last 12 months, when your child needed care right away for their CRS condition, most of the time, how long did you have to wait to get care at a CRS clinic?

☐ _____ days

☐ _____ weeks

☐ _____ months

☐ I could not get an appointment

9. In the last 12 months, how many times did your child go to an emergency room for their CRS condition?

- ⁰☐ None
¹☐ 1
²☐ 2
³☐ 3
⁴☐ 4
⁵☐ 5 to 9
⁶☐ 10 or more

10. In the last 12 months, not counting the times your child needed care right away, how satisfied were you with how long it took to get an appointment at a CRS clinic as soon as you wanted?

- ¹☐ Very satisfied
²☐ Satisfied
³☐ Dissatisfied
⁴☐ Very dissatisfied
⁵☐ I did not try to get an appointment
➔ Go to Question 12

11. In the last 12 months, when you called to schedule an appointment for your child at the CRS clinic, most of the time, how long did you have to wait for an appointment?

- ☐ _____ days
☐ _____ weeks
☐ _____ months
☐ I could not get an appointment

12. In the last 12 months, not counting the times your child went to an emergency room, how many times did your child go to the CRS clinic?

- ⁰☐ None ➔ Go to Question 30
¹☐ 1
²☐ 2
³☐ 3
⁴☐ 4
⁵☐ 5 to 9
⁶☐ 10 or more

13. In the last 12 months, when you had an appointment at the CRS clinic, how long after your appointment time, did your child have to wait to be taken to the exam room?

- ¹☐ Less than 15 minutes
²☐ 15 – 30 minutes
³☐ 31 – 45 minutes
⁴☐ 46 – 60 minutes
⁵☐ More than an hour

14. In the last 12 months, how often did office staff at your child's CRS clinic treat you and your child with courtesy and respect?

- ¹☐ Never
²☐ Sometimes
³☐ Usually
⁴☐ Always

15. In the last 12 months, how often were office staff at your child's CRS clinic as helpful as you thought they should be?

- ☐ ¹ Never
- ☐ ² Sometimes
- ☐ ³ Usually
- ☐ ⁴ Always

16. In the last 12 months, how often did the CRS clinic staff listen carefully to you?

- ☐ ¹ Never
- ☐ ² Sometimes
- ☐ ³ Usually
- ☐ ⁴ Always

17. In the last 12 months, how often did you have a hard time speaking with or understanding your CRS doctors or other health providers because they spoke different languages?

- ☐ ¹ Never
- ☐ ² Sometimes
- ☐ ³ Usually
- ☐ ⁴ Always

18. In the last 12 months, how often did your child's CRS doctors or other health providers explain things in a way you could understand?

- ☐ ¹ Never
- ☐ ² Sometimes
- ☐ ³ Usually
- ☐ ⁴ Always

19. In the last 12 months, how often did your child's CRS doctors or other health providers show respect for what you had to say?

- ☐ ¹ Never
- ☐ ² Sometimes
- ☐ ³ Usually
- ☐ ⁴ Always

20. In the last 12 months, how often did your child's CRS doctors or other health providers make it easy for you to discuss your questions or concerns?

- ☐ ¹ Never
- ☐ ² Sometimes
- ☐ ³ Usually
- ☐ ⁴ Always
- ☐ ⁵ I didn't have any questions → **Go to Question 22**

21. In the last 12 months, how often did you have your questions answered by your child's CRS doctors or other health providers?

- ☐ ¹ Never
- ☐ ² Sometimes
- ☐ ³ Usually
- ☐ ⁴ Always

22. In the last 12 months, how often did you get the specific information you needed from your child's CRS doctors or other health providers?

- ☐ ¹ Never
- ☐ ² Sometimes
- ☐ ³ Usually
- ☐ ⁴ Always
- ☐ ⁵ I didn't need any information

23. In the last 12 months, were any decisions about your child's health care made during your CRS visits?

¹☐ Yes

⁰☐ No → If No, Go to Question 27

24. When decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers offer you choices about your child's health care?

¹☐ Never

²☐ Sometimes

³☐ Usually

⁴☐ Always

25. When decisions were made in the last 12 months, how often did your child's doctors or other health providers ask you to tell them what choices you prefer?

¹☐ Never

²☐ Sometimes

³☐ Usually

⁴☐ Always

26. When decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers involve you as much as you wanted?

¹☐ Never

²☐ Sometimes

³☐ Usually

⁴☐ Always

27. Using any number from 0 to 10, where 0 is the worst health care possible, and 10 is the best health care possible, what number would you use to rate all your child's CRS health care in the last 12 months?

⁰☐ 0 Worst health care possible

¹☐ 1

²☐ 2

³☐ 3

⁴☐ 4

⁵☐ 5

⁶☐ 6

⁷☐ 7

⁸☐ 8

⁹☐ 9

¹⁰☐ 10 Best health care possible

28. An interpreter is someone who repeats or signs what one person says in a language used by another person.

In the last 12 months, did you need an interpreter to help you speak with your child's CRS doctors or other health providers?

¹☐ Yes

⁰☐ No → If No, Go to Question 30

29. In the last 12 months, when you needed an interpreter to help you speak with your child's CRS doctors or other health providers, how often did you get one?

¹☐ Never

²☐ Sometimes

³☐ Usually

⁴☐ Always

30. In general, how would you rate your child's overall health now?

- ¹ ☐ Excellent
- ² ☐ Very Good
- ³ ☐ Good
- ⁴ ☐ Fair
- ⁵ ☐ Poor

31. Is your child of Hispanic or Latino origin or descent?

- ¹ ☐ Yes, Hispanic or Latino
- ⁰ ☐ No, Not Hispanic or Latino

32. What is your child's race? Please mark one or more.

- ¹ ☐ White
- ² ☐ Black or African-American
- ³ ☐ Asian
- ⁴ ☐ Native Hawaiian or other Pacific Islander
- ⁵ ☐ American Indian or Alaska Native
- ⁶ ☐ Other

33. Are you male or female?

- ¹ ☐ Male
- ⁰ ☐ Female

34. What is the highest grade or level of school that you have completed?

- ¹ ☐ 8th grade or less
- ² ☐ Some high school, but did not graduate
- ³ ☐ High school graduate or GED
- ⁴ ☐ Some college or 2-year degree
- ⁵ ☐ 4-year college graduate
- ⁶ ☐ More than 4-year college degree

35. What language do you mainly speak at home?

- ¹ ☐ English
- ² ☐ Spanish
- ³ ☐ Some other language
(*please print*) _____

36. What language does your child mainly speak at home?

- ¹ ☐ English
- ² ☐ Spanish
- ³ ☐ Some other language
(*please print*) _____

37. How are you related to the child?

- ¹ ☐ Mother or father
- ² ☐ Grandparent
- ³ ☐ Aunt or uncle
- ⁴ ☐ Older brother or sister
- ⁵ ☐ Other relative
- ⁶ ☐ Legal guardian
- ⁷ ☐ Someone else (*please print*)

Thank you for completing this survey

APPENDIX C: COMPLETE BREAKDOWN OF RESULTS STATEWIDE

1. In the last 12 months, did your child see a CRS specialty doctor?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	64	16.2	16.4	16.4
	Yes	327	82.8	83.6	100.0
	Total	391	99.0	100.0	
Missing	System	4	1.0		
Total		395	100.0		

2. In the past 12 months, did you try to get an appointment with a CRS specialty doctor?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	47	73.4	77.0	77.0
	Yes	14	21.9	23.0	100.0
	Total	61	95.3	100.0	
Missing	System	3	4.7		
Total		64	100.0		

3. In the last 12 months, how much of a problem, if any, was it to see a CRS specialty doctor that your child needed to see?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	A big problem	28	7.2	8.2	8.2
	A small problem	51	13.0	15.0	23.2
	Not a problem	262	67.0	76.8	100.0
	Total	341	87.2	100.0	
Missing	System	50	12.8		
Total		391	100.0		

4. Using any number from 0 to 10, where 0 is the worst specialist possible, and 10 is the best specialist possible, what number would you use to rate your child's specialty doctor?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 to 3	5	1.5	1.5	1.5
	4 to 7	40	12.2	12.2	13.8
	8 to 10	282	86.2	86.2	100.0
	Total	327	100.0	100.0	

Mean = 8.9, Standard Deviation = 1.7

5. In the last 12 months, did you call the CRS clinic during regular clinic hours to get help or advice for your child?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	246	62.3	63.9	63.9
	Yes	139	35.2	36.1	100.0
	Total	385	97.5	100.0	
Missing	System	10	2.5		
Total		395	100.0		

6. In the last 12 months, when you called during regular CRS clinic hours, how often did you get the help or advice you needed for your child?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	9	6.5	6.5	6.5
	Sometimes	20	14.4	14.4	20.9
	Usually	25	18.0	18.0	38.8
	Always	85	61.2	61.2	100.0
	Total	139	100.0	100.0	

7. In the last 12 months, when your child needed care right away for their CRS condition, how satisfied were you with how long it took to get care as soon as you wanted at a CRS clinic?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Satisfied	46	11.6	11.8	11.8
	Satisfied	66	16.7	16.9	28.7
	Dissatisfied	18	4.6	4.6	33.3
	Very Dissatisfied	7	1.8	1.8	35.1
	My child did not need urgent care	253	64.1	64.9	100.0
	Total	390	98.7	100.0	
Missing	System	5	1.3		
Total		395	100.0		

8. In the last 12 months, when your child needed care right away for their CRS condition, most of the time, how long did you have to wait to get care at a CRS clinic?

		Frequency	Percent	Valid Percent	Cumulative Percent
	Within 1 day	47	34.3	43.1	43.1
	Within 2 days	16	11.7	14.7	57.8
	Within 3 days	8	5.8	7.3	65.1
	4-7 days	13	9.5	11.9	77.1
	More than 7 days	25	18.2	22.9	100.0
	Total	109	79.6	100.0	
Missing	System	21	15.3		
Unable to get care		7	5.1		
Total		137	100.0		

9. In the last 12 months, how many times did your child go to an emergency room for their CRS condition?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	None	316	80.0	80.8	80.8
	1	42	10.6	10.7	91.6
	2	14	3.5	3.6	95.1
	3	9	2.3	2.3	97.4
	4	3	.8	.8	98.2
	5 to 9	5	1.3	1.3	99.5
	10 or more	2	.5	.5	100.0
	Total	391	99.0	100.0	
Missing	System	4	1.0		
Total		395	100.0		

10. In the last 12 months, not counting the times your child needed care right away, how satisfied were you with how long it took to get an appointment at a CRS clinic as soon as you wanted?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Satisfied	76	19.2	19.5	19.5
	Satisfied	123	31.1	31.5	51.0
	Dissatisfied	44	11.1	11.3	62.3
	Very Dissatisfied	22	5.6	5.6	67.9
	I did not try to get an appointment	125	31.6	32.1	100.0
	Total	390	98.7	100.0	
Missing	System	5	1.3		
Total		395	100.0		

11. In the last 12 months, when you called to schedule an appointment for your child at the CRS clinic, most of the time, how long did you have to wait for an appointment?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	45 Days or less	144	54.3	61.0	61.0
	46 to 90 days	31	11.7	13.1	74.2
	More than 90 days	61	23.0	25.8	100.0
	Total	236	89.1	100.0	
Missing	System	18	6.8		
Could not get an appointment		11	41.5		
Total		265	100.0		

Mean = 57.0 days Standard Deviation = 81.2

12. In the last 12 months, not counting the times your child went to an emergency room, how many times did your child go to the CRS clinic?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	None	84	21.3	21.5	21.5
	1	66	16.7	16.9	38.4
	2	70	17.7	17.9	56.3
	3	43	10.9	11.0	67.3
	4	39	9.9	10.0	77.2
	5 to 9	61	15.4	15.6	92.8
	10 or more	28	7.1	7.2	100.0
	Total	391	99.0	100.0	
Missing	System	4	1.0		
Total		395	100.0		

13. In the last 12 months, when you had an appointment at the CRS clinic, how long after your appointment time, did your child have to wait to be taken to the exam room?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than 15 minutes	95	30.9	31.1	31.1
	15-30 minutes	134	43.6	43.9	75.1
	31-45 minutes	34	11.1	11.1	86.2
	46-60 minutes	19	6.2	6.2	92.5
	More than an hour	23	7.5	7.5	100.0
	Total	305	99.3	100.0	
Missing	System	2	.7		
Total		307	100.0		

14. In the last 12 months, how often did office staff at your child's CRS clinic treat you and your child with courtesy and respect?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Sometimes	9	2.9	3.0	3.0
	Usually	40	13.0	13.2	16.1
	Always	255	83.1	83.9	100.0
	Total	304	99.0	100.0	
Missing	System	3	1.0		
Total		307	100.0		

15. In the last 12 months, how often were office staff at your child's CRS clinic as helpful as you thought they should be?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	1	.3	.3	.3
	Sometimes	17	5.5	5.6	5.9
	Usually	63	20.5	20.7	26.6
	Always	223	72.6	73.4	100.0
	Total	304	99.0	100.0	
Missing	System	3	1.0		
Total		307	100.0		

16. In the last 12 months, how often did the CRS clinic staff listen carefully to you?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	3	1.0	1.0	1.0
	Sometimes	21	6.8	6.9	7.9
	Usually	45	14.7	14.8	22.6
	Always	236	76.9	77.4	100.0
	Total	305	99.3	100.0	
Missing	System	2	.7		
Total		307	100.0		

17. In the last 12 months, how often did you have a hard time speaking with or understanding your CRS doctors or other health providers because they spoke different languages?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	268	87.3	87.6	87.6
	Sometimes	18	5.9	5.9	93.5
	Usually	5	1.6	1.6	95.1
	Always	15	4.9	4.9	100.0
	Total	306	99.7	100.0	
Missing	System	1	.3		
Total		307	100.0		

18. In the last 12 months, how often did your child's CRS doctors or other health providers explain things in a way you could understand?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	6	2.0	2.0	2.0
	Sometimes	19	6.2	6.2	8.2
	Usually	40	13.0	13.1	21.3
	Always	240	78.2	78.7	100.0
	Total	305	99.3	100.0	
Missing	System	2	.7		
Total		307	100.0		

19. In the last 12 months, how often did your child's CRS doctors or other health providers show respect for what you had to say?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	3	1.0	1.0	1.0
	Sometimes	17	5.5	5.6	6.5
	Usually	51	16.6	16.7	23.2
	Always	235	76.5	76.8	100.0
	Total	306	99.7	100.0	
Missing	System	1	.3		
Total		307	100.0		

20. In the last 12 months, how often did your child's CRS doctors or other health providers make it easy for you to discuss your questions or concerns?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	2	.7	.7	.7
	Sometimes	22	7.2	7.2	7.9
	Usually	39	12.7	12.8	20.7
	Always	238	77.5	78.3	99.0
	I didn't have any questions	3	1.0	1.0	100.0
	Total	304	99.0	100.0	
Missing	System	3	1.0		
Total		307	100.0		

21. In the last 12 months, how often did you have your questions answered by your child's CRS doctors or other health providers?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	5	1.7	1.7	1.7
	Sometimes	23	7.6	7.7	9.3
	Usually	43	14.3	14.3	23.7
	Always	229	76.1	76.3	100.0
	Total	300	99.7	100.0	
Missing	System	1	.3		
Total		301	100.0		

22. In the last 12 months, how often did you get the specific information you needed from your child's CRS doctors or other health providers?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	8	2.6	2.6	2.6
	Sometimes	19	6.2	6.2	8.8
	Usually	39	12.7	12.7	21.6
	Always	203	66.1	66.3	87.9
	I didn't have need any information	37	12.1	12.1	100.0
	Total	306	99.7	100.0	
Missing	System	1	.3		
Total		307	100.0		

23. In the last 12 months, were any decisions about your child's health care made during your CRS visits?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	144	46.9	46.9	46.9
	Yes	163	53.1	53.1	100.0
	Total	307	100.0	100.0	

24. When decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers offer you choices about your child's health care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	18	11.0	11.2	11.2
	Sometimes	20	12.3	12.4	23.6
	Usually	29	17.8	18.0	41.6
	Always	94	57.7	58.4	100.0
	Total	161	98.8	100.0	
Missing	System	2	1.2		
Total		163	100.0		

25. When decisions were made in the last 12 months, how often did your child's doctors or other health providers ask you to tell them what choices you prefer?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	23	14.1	14.1	14.1
	Sometimes	19	11.7	11.7	25.8
	Usually	31	19.0	19.0	44.8
	Always	90	55.2	55.2	100.0
	Total	163	100.0	100.0	

26. When decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers involve you as much as you wanted?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	4	2.5	2.5	2.5
	Sometimes	13	8.0	8.0	10.4
	Usually	23	14.1	14.1	24.5
	Always	123	75.5	75.5	100.0
	Total	163	100.0	100.0	

27. Using any number from 0 to 10, where 0 is the worst health care possible, and 10 is the best health care possible, what number would you use to rate all your child's CRS health care in the last 12 months

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 to 3	6	2.0	2.0	2.0
	4 to 7	37	12.1	12.2	14.2
	8 to 10	260	84.7	85.8	100.0
	Total	303	98.7	100.0	
Missing	System	4	1.3		
Total		307	100.0		

Mean = 8.9, Standard Deviation = 1.7

28. In the last 12 months, did you need an interpreter to help you speak with your child's CRS doctors or other health providers?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	226	73.6	73.6	73.6
	Yes	81	26.4	26.4	100.0
	Total	307	100.0	100.0	

29. In the last 12 months, when you needed an interpreter to help you speak with your child's CRS doctors or other health providers, how often did you get one?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	1	1.2	1.2	1.2
	Sometimes	10	12.3	12.3	13.6
	Always	70	86.4	86.4	100.0
	Total	81	100.0	100.0	

30. In general, how would you rate your child's overall health now?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Excellent	104	26.3	26.7	26.7
	Very Good	128	32.4	32.9	59.6
	Good	106	26.8	27.2	86.9
	Fair	41	10.4	10.5	97.4
	Poor	10	2.5	2.6	100.0
	Total	389	98.5	100.0	
Missing	System	6	1.5		
Total		395	100.0		

31. Is your child of Hispanic or Latino origin or descent?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	163	41.3	41.7	41.7
	Yes	228	57.7	58.3	100.0
	Total	391	99.0	100.0	
Missing	System	4	1.0		
Total		395	100.0		

32. What is your child's race*?

	Frequency	Percent	Valid Percent	Cumulative Percent
White	135	34.2	34.2	100.0
American Indian	28	7.1		
Black	18	4.6		
Asian	4	1.0		
Hawaiian/Pacific Islander	0	0		
Other	218	55.2		
Refused to Answer	0	0		
Total	395	100.0	100.0	

* Respondents were allowed to select multiple answers.

33. Are you male or female?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	33	8.4	8.5	8.5
	Female	357	90.4	91.5	100.0
	Total	390	98.7	100.0	
Missing	System	5	1.3		
Total		395	100.0		

34. What is the highest grade or level of school that you have completed?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	8th Grade or less	47	11.9	12.2	12.2
	Some high school, but did not graduate	98	24.8	25.5	37.7
	High school graduate or GED	99	25.1	25.7	63.4
	Some college or 2-year degree	91	23.0	23.6	87.0
	4-year college graduate	38	9.6	9.9	96.9
	More than 4-year college degree	12	3.0	3.1	100.0
	Total	385	97.5	100.0	
Missing	System	10	2.5		
Total		395	100.0		

35. What language do you mainly speak at home?

	Frequency	Percent	Valid Percent	Cumulative Percent
English	233	59.0	60.1	60.1
Spanish	136	34.4	35.5	95.6
Bilingual	11	2.5	2.6	98.2
Navajo	5	1.3	1.3	99.5
Native American Dialect	1	0.2	0.2	99.6
Havasupai	1	0.2	0.2	99.8
Persian	1	0.2	0.2	100.0
Total	388	98.2	100.0	
Missing	7	1.8		
Total	395	100.0		

36. What language does your child mainly speak at home?

	Frequency	Percent	Valid Percent	Cumulative Percent
English	240	60.8	62.3	62.3
Spanish	88	22.3	22.9	85.2
Bilingual	39	9.9	10.1	95.3
Navajo	2	0.5	0.5	95.8
Havasupai	1	0.3	0.3	96.1
Persian	1	0.3	0.3	96.4
Sign Language	10	2.5	2.6	99.0
Non Verbal	4	1.0	1.0	100.0
Total	385	97.5	100.0	
Missing	10	2.5		
Total	395	100.0		

37. How are you related to the child?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Mother or father	348	88.1	89.0	89.0
	Grandparent	28	7.1	7.2	96.2
	Aunt or uncle	1	.3	.3	96.4
	Legal guardian	8	2.0	2.0	98.5
	Someone else	6	1.5	1.5	100.0
	Total	391	99.0	100.0	
Missing	System	4	1.0		
Total		395	100.0		

APPENDIX D: COMPARISON OF VALID RESPONSES BY SITE

	Question	Phoenix		Tucson		Flagstaff		Yuma		All	
1.	In the last 12 months, did your child see a CRS specialty doctor? Yes No	219 39	(84.9) (15.1)	67 16	(80.7) (19.3)	26 6	(81.3) (18.8)	15 3	(83.3) (16.7)	327 64	(82.8) (16.2)
2.	If you child did not see a CRS specialty doctor, did you try to get an appointment with a CRS specialty doctor in the last 12 months? Yes No	12 25	(32.4) (67.6)	1 15	(6.3) (93.8)	1 4	(20.0) (80.0)	- 3	(100.0)	14 47	(23.0) (77.0)
3.	In the last 12 months, how much of a problem, if any, was it to see a CRS specialty doctor that your child needed to see? A big problem A small problem Not a problem	22 37 172	(9.5) (16.0) (74.5)	2 9 57	(2.9) (13.2) (83.8)	3 4 21	(10.7) (14.3) (75.0)	1 1 12	(7.1) (7.1) (85.7)	28 51 262	(8.2) (15.0) (76.8)
4.	Using any number from 0 to 10, with 10 being the best specialist possible, what number would you use to rate your child's specialty doctor? Mean ± sd 0 - 3 4 - 7 8 - 10	8.9 ± 1.8 5 29 185	(2.3) (13.2) (84.5)	9.2 ± 1.3 - 6 61	(9.0) (91.0)	8.7 ± 1.5 - 5 21	(19.2) (80.8)	9.1 ± 1.0 - - 15	(100.0)	8.9 ± 1.7 5 40 282	(1.5) (12.2) (86.2)
5.	Did you call the CRS clinic during regular clinic hours to get help or advice for your child? Yes No	91 162	(36.0) (64.0)	28 54	(43.1) (65.9)	16 16	(50.0) (50.0)	4 14	(22.2) (77.8)	139 246	(36.1) (63.9)
6.	How often did you get the help or advice you needed for your child? Never Sometimes Usually Always	6 15 19 51	(6.6) (16.5) (20.9) (56.0)	1 2 2 23	(3.6) (7.1) (7.1) (82.1)	2 2 4 8	(12.5) (12.5) (25.0) (50.0)	- 1 - 3	(25.0)	9 20 25 85	(6.5) (14.4) (18.0) (61.2)

	Question	Phoenix		Tucson		Flagstaff		Yuma		All	
7.	When your child needed care right away for their CRS condition, how satisfied were you with how long it took to get care as soon as you wanted?										
	Very Satisfied	33	(12.8)	10	(12.0)	3	(9.4)	-		46	(12.1)
	Satisfied	49	(19.1)	14	(16.9)	1	(3.1)	2	(11.1)	66	(17.3)
	Dissatisfied	11	(4.3)	7	(8.4)	-		-		18	(4.7)
	Very Dissatisfied	5	(1.9)	-		2	(6.3)	-		7	(1.8)
	Child did not need urgent care	159	(61.9)	52	(62.7)	26	(81.3)	16	(88.9)	253	(64.9)
9.	In the last 12 months, how many times did your child go to an emergency room for their CRS condition?										
	None	207	(80.2)	70	(84.3)	25	(78.1)	14	(77.8)	316	(80.8)
	1	28	(10.9)	9	(10.8)	4	(12.5)	1	(5.6)	42	(10.7)
	2	7	(2.7)	3	(3.6)	2	(6.3)	2	(11.1)	14	(3.6)
	3	6	(2.3)	1	(1.2)	1	(3.1)	1	(5.6)	9	(2.3)
	4	3	(1.2)	-		-		-		3	(0.4)
	5 to 9	5	(1.9)	-		-		-		5	(0.7)
	10 or more	2	(0.9)	-		-		-		2	(0.5)
10.	Not counting the times your child needed care right away, how satisfied were you with how long it took to get an appointment at a CRS clinic as soon as you wanted?										
	Very Satisfied	52	(20.2)	15	(18.1)	4	(12.5)	5	(27.8)	76	(19.5)
	Satisfied	81	(31.5)	28	(33.7)	11	(34.4)	3	(16.7)	123	(31.5)
	Dissatisfied	34	(13.2)	6	(7.2)	4	(12.5)	-		44	(11.3)
	Very Dissatisfied	17	(6.6)	2	(2.4)	3	(9.4)	-		22	(5.6)
	Did not try to get an appointment	73	(28.4)	32	(38.6)	10	(31.3)	10	(55.6)	120	(31.2)
12.	In the last 12 months, not counting the times your child went to an emergency room, how many times did your child go to the CRS clinic?										
	None	50	(19.4)	21	(25.3)	6	(18.8)	7	(38.9)	84	(21.5)
	1-2	91	(34.5)	26	(31.4)	15	(46.9)	6	(33.4)	136	(34.4)
	3-4	58	(22.5)	15	(18.0)	6	(18.8)	3	(16.7)	82	(20.8)
	5 to 9	45	(17.4)	14	(16.9)	1	(3.1)	1	(5.6)	61	(15.6)
	10 or more	16	(6.2)	7	(8.4)	4	(12.5)	1	(5.6)	28	(7.2)
	Question	Phoenix		Tucson		Flagstaff		Yuma		All	

13.	In the last 12 months, when you had an appointment at the CRS clinic, how long after your appointment time did your child have to wait to be taken to the exam room?										
	Less than 15 minutes	55	(26.6)	26	(41.9)	9	(36.0)	5	(45.5)	95	(31.1)
	15-30 minutes	101	(48.8)	19	(30.6)	10	(40.0)	4	(36.4)	134	(43.9)
	31-45 minutes	21	(10.1)	9	(14.5)	2	(8.0)	2	(18.2)	34	(11.1)
	46-60 minutes	13	(6.3)	5	(8.1)	1	(4.0)	-		19	(6.2)
	More than an hour	17	(8.2)	3	(4.8)	3	(12.0)	-		23	(7.5)
14.	How often did office staff at your child's CRS clinic treat you and your child with courtesy and respect?										
	Never	-		-		-		-		-	
	Sometimes	6	(2.9)	1	(1.6)	2	(8.0)	-		9	(3.0)
	Usually	28	(13.5)	10	(16.4)	2	(8.0)	-		40	(13.2)
	Always	173	(83.6)	50	(82.0)	21	(84.0)	11	(100.0)	255	(83.9)
15.	How often were office staff members at your child's CRS clinic as helpful as you thought they should be?										
	Never	1	(0.5)	-		-		-		1	(0.3)
	Sometimes	12	(5.8)	2	(3.2)	3	(12.0)	-		17	(5.6)
	Usually	41	(19.9)	16	(25.8)	6	(24.0)	-		63	(20.7)
	Always	152	(73.8)	44	(71.0)	16	(64.0)	11	(100.0)	223	(73.4)
16.	How often did the CRS clinic staff listen carefully to you?										
	Never	2	(1.0)	1	(1.6)	-		-		3	(1.0)
	Sometimes	18	(8.7)	1	(1.6)	2	(8.0)	-		21	(6.9)
	Usually	31	(14.9)	10	(16.1)	4	(16.0)	-		45	(14.8)
	Always	157	(75.5)	50	(80.6)	19	(76.0)	10	(100.0)	236	(77.4)
17.	How often did you have a hard time speaking with or understanding your CRS doctors or other health providers because they spoke different languages?										
	Never	179	(86.1)	56	(90.3)	23	(92.0)	10	(90.9)	268	(87.6)
	Sometimes	15	(7.2)	-		2	(8.0)	1	(9.1)	18	(5.9)
	Usually	3	(1.4)	2	(3.2)	-		-		5	(1.6)
	Always	11	(5.3)	4	(6.5)	-		-		15	(4.9)

	Question	Phoenix		Tucson		Flagstaff		Yuma		All	
18.	How often did your child's CRS doctors or other health providers explain things in a way you could understand?										
	Never	6	(2.9)	-		-		-		6	(2.0)
	Sometimes	15	(7.2)	2	(3.2)	2	(8.0)	-		19	(6.2)
	Usually	25	(12.1)	8	(12.9)	6	(24.0)	1	(9.1)	40	(13.1)
	Always	161	(77.8)	52	(83.9)	17	(68.0)	10	(90.9)	240	(78.7)
19.	How often did your child's CRS doctors or other health providers show respect for what you had to say?										
	Never	2	(1.0)	1	(1.6)	-		-		3	(1.0)
	Sometimes	12	(5.8)	1	(1.6)	4	(16.0)	-		17	(5.6)
	Usually	34	(16.3)	11	(17.7)	5	(20.0)	1	(9.1)	51	(16.7)
	Always	160	(76.9)	49	(79.0)	16	(64.0)	10	(90.9)	235	(76.8)
20.	How often did your child's CRS doctors or other health providers make it easy for you to discuss your questions or concerns?										
	Never	2	(1.0)	-	(4.8)	-		-		2	(0.7)
	Sometimes	14	(6.8)	3	(17.7)	4	(16.0)	1	(9.1)	22	(7.2)
	Usually	24	(11.7)	11	(74.2)	3	(12.0)	1	(9.1)	39	(12.8)
	Always	165	(80.1)	46	(74.2)	18	(72.0)	9	(81.8)	238	(78.3)
21.	How often did you have your questions answered by your child's CRS doctors or other health providers?										
	Never	5	(2.5)	-		-		-		5	(1.7)
	Sometimes	14	(6.9)	4	(6.7)	4	(16.0)	1	(9.1)	23	(7.7)
	Usually	26	(12.7)	14	(23.3)	2	(8.0)	1	(9.1)	43	(14.3)
	Always	159	(77.9)	42	(70.0)	19	(76.0)	9	(81.8)	229	(76.3)
22.	How often did you get the specific information you needed from your child's CRS doctors or other health providers?										
	Never	8	(3.8)	-		-		-		8	(2.6)
	Sometimes	12	(5.8)	3	(4.8)	3	(12.0)	1	(9.1)	19	(6.2)
	Usually	23	(11.1)	12	(19.4)	3	(12.0)	1	(9.1)	39	(12.7)
	Always	139	(66.8)	41	(66.1)	15	(60.0)	8	(72.7)	203	(66.3)
	Didn't need any information	26	(12.5)	6	(9.7)	4	(16.0)	1	(9.1)	36	(11.8)

	Question	Phoenix		Tucson		Flagstaff		Yuma		All	
23.	In the last 12 months, were any decisions about your child's health care made during your CRS visits?										
	Yes	109	(52.4)	27	(43.5)	22	(84.6)	5	(45.5)	163	(53.1)
	No	99	(47.6)	35	(56.5)	4	(15.4)	6	(54.5)	144	(46.9)
24.	If decisions were made, how often did your child's CRS doctors or other health providers offer you choices about your child's health care?										
	Never	15	(13.8)	1	(4.0)	2	(9.1)	0		18	(11.2)
	Sometimes	15	(13.8)	2	(8.0)	2	(9.1)	1	(20.0)	20	(23.6)
	Usually	19	(17.4)	4	(16.0)	6	(27.3)	-		29	(18.0)
	Always	60	(55.0)	18	(72.0)	12	(54.5)	4	(80.0)	94	(58.4)
25.	If decisions were made, how often did your child's doctors or other health providers ask you to tell them what choices you prefer?										
	Never	21	(19.3)	-		2	(9.1)	-		23	(14.1)
	Sometimes	14	(12.8)	3	(11.1)	1	(4.5)	1	(20.0)	19	(11.7)
	Usually	17	(15.6)	8	(29.6)	6	(27.3)	-		31	(19.0)
	Always	57	(52.3)	16	(59.3)	13	(59.1)	4	(80.0)	90	(55.2)
26.	If decisions were made, how often did your child's CRS doctors or other health providers involve you as much as you wanted?										
	Never	3	(2.8)	-		1	(4.5)			4	(2.5)
	Sometimes	10	(9.2)	2	(7.4)	1	(4.5)			13	(8.0)
	Usually	16	(14.7)	5	(18.5)	2	(9.1)			23	(14.1)
	Always	80	(73.4)	20	(74.1)	18	(81.8)			123	(75.5)

	Question	Phoenix		Tucson		Flagstaff		Yuma		All	
27.	Using any number from 0 to 10, with 10 being the best healthcare possible, what number would you use to rate all your child's CRS health care in the last 12 months? Mean ± sd	8.9 ± 1.7		9.1±1.1		8.6 ± 1.8		9.1±1.4		8.9±1.6	
	0 - 3	5	(2.4)	-		1	(3.8)	-		6	(2.0)
	4 - 7	23	(11.2)	8	(13.1)	4	(15.4)	2	(18.2)	37	(12.2)
	8 - 10	177	(86.3)	53	(86.9)	21	(80.8)	9	(81.8)	260	(85.8)
28.	Did you need an interpreter to help you speak with your child's CRS doctors or other health providers? Yes	61	(29.3)	13	(21.0)	2	(7.7)	5	(45.5)	81	(26.4)
	No	147	(70.7)	49	(79.0)	24	(92.3)	6	(54.5)	226	(73.6)
29.	When you need an interpreter to help you speak with your child's CRS doctors or other health providers, how often did you get one? Never	-		-		1	(50.0)	-		1	(1.2)
	Sometimes	8	(13.1)	2	(15.4)	-		-		10	(12.3)
	Usually	-		-		-		-		-	
	Always	53	(86.9)	11	(84.6)	1	(50.0)	5	(100.0)	70	(86.4)
30.	In general, how would you rate your child's overall health now? Excellent	61	(23.7)	28	(34.1)	9	(29.0)	6	(31.6)	104	(26.7)
	Very Good	84	(32.7)	26	(31.7)	10	(32.3)	8	(42.1)	128	(32.9)
	Good	76	(29.6)	19	(23.2)	8	(25.8)	3	(15.8)	106	(26.8)
	Fair	30	(11.7)	7	(8.5)	2	(6.5)	2	(10.5)	41	(10.4)
	Poor	6	(2.3)	2	(2.4)	2	(6.5)	-		10	(2.6)